A COMPARISON OF HEALTH-RELATED QUALITY OF LIFE AND INFORMANT PERSPECTIVES IN SYMPTOMS REPORTING AMONG CHILDREN WITH FUNCTIONAL AND ORGANIC GASTROINTESTINAL DISORDERS

A Thesis

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ABSTRACT

Scant research exists regarding the nature of variance in overall level of Health-Related Quality of Life (HRQOL) and parent-child informant perspectives of HRQOL specific to children with functional and organic gastrointestinal (GI) disorders and across child ages. Also, a trend has emerged for using discrepancies of informant perspectives to make predictions regarding pediatric chronic illness, but this approach has yet to be applied to children with GI disorders. The current study investigated generic HRQOL and informant discrepancies in generic HRQOL among children (N = 548) from nine hospitals across the U.S. with functional or organic GI disorder types. HRQOL was measured using child self-reports and parent proxy-reports from the Pediatric Quality of Life Inventory™ 4.0 Generic Core Scales (PedsQL™). Intraclass correlation coefficients (ICC's) of parent-child agreement for each age group (5-7 years, 8-12 years, and 13-18 years), and age by GI disorder type were calculated. In addition, item-level analyses of dyadic parent-child informant discrepancies were calculated for use in prediction of specific GI disorders and GI disorder types.

Children with organic GI disorders were found to have higher HRQOL than children with functional GI disorders. ICC's revealed moderate to high parent-child agreement for HRQOL ratings across age groups and age group by GI disorder type, in addition to similar agreement between GI disorder types. An interesting trend was revealed among age groups. Children ages 8-12 years showed consistently highest agreement across and within GI disorders types above that of children ages 5-7 years and youth ages 13-18 years. Item level analyses of discrepancies revealed a greater likelihood of higher discrepancy scores for children with functional GI disorders than organic GI disorders. These findings provide insight into trends with regard to parent-child informant reports and notable differences in HRQOL between GI disorder types.

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1. INTRODUCTION

1.1 Health-Related Quality of Life

The phrase "quality of life" is a generic term that refers to a broad overview of life functioning, encompassing many advantages, disadvantages, positives and negatives in life (see Guyatt, Feeny, & Patrick, 1993 for review). Some may think that narrowing one's scope of interest to Health-Related Quality of Life (HRQOL) would lessen the open-endedness of this expression for a more parsimonious definition, but a widely-agreed upon definition of HRQOL historically has been a challenge (Guyatt, Feeny, & Patrick, 1993; Matza, Swensen, Flood, Secnik, & Leidy, 2004; Spieth & Harris, 1996). Ultimately, HRQOL has been conceptualized within pediatric psychology with regard to aspects of quality of life associated with health that can be considered and/or influenced within the context of healthcare services (see Varni and Limbers, 2009 for a review) .

The current generally accepted definition of HRQOL incorporates a multidimensional construct (Eiser & Morse, 2001b; Leidy, Revicki, & Genesté, 1999; Matza et al., 2004; Varni & Limbers, 2009) including dimensions related to physical, psychological, and social functioning (Leidy et al., 1999; Varni & Limbers, 2009). These minimum domains are as specified by the World Health Organization, with psychological domain encompassing both cognitive and emotional functioning (see Varni and Limbers, 2009 for a review).

Although this definition has extensive support within pediatric psychology, a definition of HRQOL from Spieth and Harris (1996) offers a perspective more directly from the healthcare field. This perspective views HRQOL as "the subjective and objective impact of dysfunction associated with an illness or injury, medical treatment, and healthcare policy (p. 176)." This definition is presented to introduce and provide a background for HRQOL from its origins in healthcare, because this is the context from which its conceptualization originates (Eiser & Morse, 2001c). Eiser and Morse (2001b) argue that a need to refine this concept came about from improvements in treatment of illness due to improvements in modern medicine. Due to healthcare advances, death and critical conditions are less of a typical outcome for diseases, and fortunately, prevention and management of chronic health conditions are the norm (Eiser & Morse, 2001c; Spieth & Harris, 1996). Consideration of HRQOL is integral to the assessment of

medical interventions and treatments (Eiser & Morse, 2001c), and to an understanding of the lives of increasing numbers of people living with and managing chronic health conditions (Harding, 2001).

1.2 HRQOL and Children with Chronic Health Conditions

Taking into consideration developmental variables and milestones necessary for adjustment unique to children and adolescents as compared to adults, assessing and understanding HRQOL is essential for youth during this progression through life (Hooper, Hynd, & Mattison, 2013). This becomes even more important after considering the plethora of literature aimed at understanding HRQOL in children with chronic health conditions. For example, Varni, Limbers, and Burwinkle (2007) assessed HRQOL using the Pediatric Quality of Life Inventory™ (PedsQL™) 4.0 Generic Core Scales in 2,500 pediatric patients affected by various chronic health conditions and 9,500 healthy comparison children. Results showed that children with asthma, diabetes, cancer, renal disease, gastrointestinal conditions, cardiac disease, obesity, cerebral palsy, and rheumatology showed significantly lower rates of self-reported HRQOL relative to healthy children. Patients with cerebral palsy had the lowest self-reported HRQOL and children with diabetes had the highest self-reported HRQOL relative to all other children with chronic health conditions.

Ingresky et al. (2010) examined differences among 589 pediatric patients (ages 2 to 18 years) with obesity, eosinophilic gastrointestinal disorder, inflammatory bowel disease, epilepsy, diabetes, sickle cell disease, post-renal transplantation, and cystic fibrosis. Self-report and parent proxy-report forms of the PedsQL™ 4.0 Generic Core Scales were completed to assess HRQOL. Results showed differences in HRQOL to be most prominent for parent proxy-report. Although several differences emerged across groups and subscales of HRQOL, pediatric patients with eosinophilic gastrointestinal and obesity had significantly lower parent proxy-reported HRQOL than all other diagnostic groups.

Studies reviewed here represent only a small portion of findings related to HRQOL in children with chronic health conditions. Many other studies have investigated specific chronic health conditions in children and each usually included findings that these children have lower overall HRQOL relative to healthy comparison children. For example, physical conditions studied have included cerebral palsy (Varni et al., 2005), irritable bowel syndrome (Varni et al., 2006), obesity (Swallen, Reither, Haas, & Meier,

2005), traumatic brain injury (Stancin et al., 2002), asthma (Juniper et al, 1996), cancer (Russell, Hudson, Long, & Phipps, 2006), low birth weight (Saigal et al., 1994), celiac disease (Kolsteren, Koopman, Schalekamp, & Mearin, 2001), and problems of sleep (Rosen, Palermo, Larkin, & Redline, 2002).

1.3 HRQOL and GI Disorders

Based on the literature reviewed here, pediatric chronic health conditions are generally debilitating not only within the symptoms and dysfunction specific to a particular disease, but across various facets in life, resulting in impairment in overall HRQOL. Gastrointestinal (GI) disorders are of particular interest when considering chronic health conditions due to their prevalence and the variety of ways in which they can manifest. A review by Rentz et al. (2001) reported 8 to15 % of US citizens exhibit symptoms of gastroesophageal disease, 14 to 32 % exhibit symptoms of dyspepsia, and 9 to 22 % experience symptoms of irritable bowel syndrome. For youth under 20 years of age, one study found a prevalence of 43 per 100,000, and 28 per 100,000 for Crohn's disease and ulcerative colitis, respectively (Kappelman et al., 2007). This study also found a prevalence of 201 in 100,000, and 238 per 100,000 for Crohn's disease and ulcerative colitis, respectively, for adults. Not only are GI disorders pervasive, an elevated concern about GI disorders also stems from the wide range in which they may present. For example, several different diagnosable GI disorders are identified within two basic types: functional GI disorders (FGID), and organic GI disorders (OGID; see Costa, Mumolo, & Bellini, 2007 for a review). FGIDs and OGIDs are differentiated based on the conclusiveness of their medical origin. OGIDs are attributed to testable biochemical or structural abnormalities, whereas the medical etiology of FGIDs is unclear. Common FGIDs include functional constipation, functional abdominal pain, functional dyspepsia, and irritable bowel syndrome (Drossman, 2006).

Common FGIDs include functional constipation, functional abdominal pain, functional dyspepsia, irritable bowel syndrome (see Drossman et al., 2006 for details of FGIDs). According to Banez and Cunningham (2009), common OGIDs include Crohn's disease (i.e., inflammation of the digestive track occurring anywhere from the mouth to the skin around the anus, co-occurring with mucosal inflammation), ulcerative colitis (i.e., inflammation of the colon affecting the inner lining of the mucosal wall), and

indeterminate colitis (i.e., condition symptomatic of Crohn's disease and/or ulcerative colitis diagnosed as indeterminate colitis until a more specific diagnosis can be made).

Assessment of HRQOL within the context of these GI conditions is foundational to research. For example, Greenley et al. (2013) found children (11 to 18 years old) with irritable bowel disease, including Crohn's disease and ulcerative colitis, and abdominal pain had impaired HRQOL. In addition, Varni et al. (2006) found that children with irritable bowel syndrome (a FGID) self-reported lower HRQOL than healthy children. Most of the extant literature on pediatric GI disorders and HRQOL is provided in this review. Furthermore, little research exists beyond what has been reviewed here regarding GI disorders and HRQOL specific to children. However, literature specific to GI disorders and HRQOL for adults suggests at least similar deleterious impact of GI dysfunction on HRQOL for children. For example, Halder et al. (2004) investigated HRQOL in 122 adults (*M* age = 36 years; 58 % female) with functional gastrointestinal disorders, including dyspepsia and irritable bowel syndrome. Results demonstrated lower HRQOL for patients with irritable bowel syndrome and dyspepsia. However, results were less conclusive for patients with irritable bowel syndrome as analyses showed that this impairment could be attributed to psychologically-related confounds. In contrast, a review of 12 studies by El-Shirag, Olden, and Bjorkman (2002) offered more substantial support in 11 studies for impaired HRQOL in patients with irritable bowel syndrome relative to healthy adults. In addition, a review of 12 studies by El-Serag, and Talley (2003) also provided further support for impairment in HRQOL for adults with functional dyspepsia as compared to healthy controls. Also, Cohen (2002) reviewed 22 studies of HRQOL in the OGID, Crohn's Disease and found that adults with Crohn's disease also generally have worse HRQOL relative to healthy controls.

1.4 Informant Perspectives

Although the literature on HRQOL and GI disorders in adults is compelling and makes evident the impairment in these individuals, the current study focuses on pediatric GI disorders for two reasons. First, as explained previously, children are especially affected by the unfolding of development, which may exacerbate their impairment in HRQOL. Second, information on pediatric GI problems and dysfunction is usually generated through multiple informants (i.e., parent proxy-report, child self-report).

A large portion of HRQOL literature features scale development and psychometrics. Within this area, the quality of information provided by each informant and the similarities and differences of informants' perspective has emerged as a theme (Eiser & Morse, 2001a; Jokovic, Locker, & Guyatt, 2004; Juniper, Guyatt, Feeny, Griffith, & Ferrie, 1997; Theunissen et al., 1998; Upton, Lawford, & Eiser, 2008; Varni, Limbers, & Burwinkle, 2007). Within the HRQOL literature, "informant," refers to the person providing information about the participant, patient, or client being assessed, and may even refer to the client himself/herself. As explained previously, since researchers of pediatric HRQOL often focus on the patient-perspective, self- report is weighted heavily (see Matza et al., 2004 for a review).

For example, Varni, Limbers, and Burwinkle (2007) investigated how psychometric performance in reporting of quality of child perspective varied with age among 8,591 chronically ill and healthy children ages 5 to 18 years. HRQOL was assessed using the generic PedsQL^{TM} 4.0 Generic Core Scales. Children 5 to 7 years old completed the PedsQL^{TM} with assistance from parents and children 8 to18 years old completed it independently. Across age groups, good reliability and validity was maintained, which provided great support for valuing child self-report in youngsters as young as 5 years of age.

Furthermore, the quality of parents as informants of child HRQOL has been considered (Eiser & Morse, 2001a; Jokovic et al., 2004) primarily as it relates to the child/patient perspective. In other words, quality of parental perspective on child HRQOL has been considered by examining discrepancies and agreement between child and parent informants (Upton et al., 2008).

Eiser and Morse's (2001a) literature review regarding parent and child agreement on HRQOL found that parent-child agreement was higher for domains related to physical health and less for emotional and social domains. This may be because physical health is more directly observable for a parent, whereas a good assessment of emotional functioning requires articulation of emotion by the child, which may be difficult for young children in particular. Further, parents may not be around their school-aged child and his/her peers enough to assess social functioning in the same way as the child. Also, agreement was greater for chronically ill children than healthy children. This may be because parents who take responsibility for managing their child's chronic health condition have obvious indicators of their child's HRQOL, such as apparent problems with physical health and the negative emotions that may be co-

occurring. In contrast, parents of healthy children may have less obvious indicators available to assess the variance in their child's HRQOL, as their child understands it. Also, parents of children with a chronic health conditions are likely to just be around their children more, as care for their child's chronic health condition mighty necessitate. Healthy children are likely to be more independent and in school away from their parents, which would not allow parents as much time and exposure with the child to learn as much about his/her child's perspective.

Nevertheless, although parents of children with chronic health conditions tend to have greater agreement with their child on his/her HRQOL than parents of healthy children, one must keep in mind that a variance in perspective still remains within both parents of healthy children and parents of children with chronic health conditions. A review by Upton, Lawford, and Eiser (2008) pointed out that a recurring theme in the literature is that parents of children with chronic health conditions tended to underestimate their children's HRQOL relative to the children's perspective, and parents of healthy children tended to overestimate their child's HRQOL relative to the child's perspective.

A review by Eiser and Varni (2013) discussed child and parent characteristics, which shed light on potential reasons and empirically supported reasons for differences in parent and child perspective on child HRQOL. The authors explained that younger children (i.e., toddler and younger) spend much more time with their parents than school-aged children, which may foster a greater agreement in parent-child perspectives. However, preschoolers' developmental level may make it difficult for them to speak about their emotional well-being. Therefore, they may not be able to self-report a perspective exactly parallel to parent proxy on this important facet of their HRQOL. In addition, Eiser and Varni (2013) noted that empirical literature supports that parents' well-being and functioning may affect their perception of their children's HRQOL in such a way that parents experiencing emotional distress (i.e., depression) are likely to report a more negative view of their child's HRQOL. Ultimately, these authors emphasized the overall limitations of a parent's perspective on his/her child's functioning. From the time of school age and through adolescence, children are away from their parents in very influential environments. These individual experiences away from parental supervision serve to create increasingly larger gaps in parent-child perspectives of the child's social, emotional, and physical well-being. Even a healthy and thorough

amount of communication between parent and child leaves out vital nuances that may never be fully understood by a parent.

Additionally, behavioral health, which can be an integral mechanism for influencing overall HRQOL, may be something that is also a mechanism for influencing parent-child agreement. Yeh and Weisz (2001) independently assessed parents and 381 children referred for outpatient mental health services. Agreement was examined between each child and his/her parent on target problems to be addressed in treatment. For 63% of parent-child dyads, not even one target problem was agreed upon. Even when target problems were grouped into general categories, one-third of dyads still did not agree on a single category. Furthermore, agreement was less for internalizing categories versus externalizing categories. Although this was a sample of children receiving outpatient behavioral health services, and not a sample of children coping with chronic health conditions, parallels can be made between the two in terms of informant agreement. HRQOL measures are often used to assess pediatric samples and this includes an evaluation of any emotional and psychosocial problems co-occurring with chronic health conditions. This is because emotional and psychosocial problems often do co-occur with chronic health conditions, and, essentially, these children experience problems with mental health, in addition to problems with physical health. Given the findings of Yeh and Wesz (2001), it is apparent that children experiencing behavioral health problems often do not agree with their parents on those problems. Perhaps, children with chronic health conditions, who also often experience psychosocial adjustment concerns related to their chronic health condition, might have at least some notable disagreement with their parents about their functioning, as was evident in Yeh and Wesz (2001), which may influence parent-report and child self-report agreement.

Whatever the reason may be that parents and children do not completely agree when assessing pediatric HRQOL, much may be learned from this variance in perspectives. In fact, in discussing informant perspectives and child depression, Cole and Martin (2005) explained, “a strength of parent reports may be that parents provide a broader and more stable picture of the child. A weakness is that parents may be relatively naïve about their child’s internal state at any specific time. This combination of strengths and weaknesses suggests that parents may be better informants about more stable trait-like

dimensions of depression than about less stable timespecific dimensions. (p. 145)." This point of view can be applied to informant perspectives on HRQOL, and provides one way in which researchers or clinicians can differentially value or apply informant reports for what each may have to offer.

1.5 Assessing Informant Perspectives

Literature aimed at understanding variance in informant perspectives on aspects of child or adolescent functioning includes three different types of psychometric approaches (Achenbach, 2011; Upton et al., 2008). The first approach examines differences in agreement using means and standard deviations, and consistency between informants perspectives using product moment correlation with Pearson's *r*. Means and standard deviations provide insight into significant or non-significant differences across informants and the direction of differences, although effect sizes are also used to detect magnitude of difference (Deyo, Diehr, & Patrick, 1991; Kramer & Feinstein, 1981). In other words, comparing means and standard deviations informs investigators as to whether informants (i.e., parent and child) provide meaningfully different ratings of HRQOL and which informants providing ratings that are relatively higher or lower. In a review of parent and child informant perspectives regarding HRQOL, 17 of the 19 studies assessed found differences between parent and child (Upton et al., 2008). However, only 2 of the 17 studies found "significant" differences and in opposing directions, which suggests mixed findings using this type of analysis. Additionally, the product moment correlation provides information as to the linear relationship of the informant ratings (Deyo et al., 1991; Kramer & Feinstein, 1981). This correlation measures general trends between informants and is sensitive to how similarly informant ratings increase and decrease in the same way. Although the use of this correlation and comparisons of means and standard deviations have been used (see Upton et al., 2008 for a review) to be indicative of the degree to which informants agree, it would be best to generally describe the statistical approach in which they are utilized to be a measure of *relatedness*. This is because the combination of these psychometric analyses are non-exhaustive and do not provide a complete picture for describing informant agreement or concordance.

The main statistical limitation from this relatedness approach is that it does not account for systematic difference among informants ratings (Deyo et al., 1991; McGraw & Wong, 1996). A systematic difference refers to a consistent discrepancy between ratings among informants. For example, if on every

item in a HRQOL questionnaire a mother rated her son two units lower than the son rated himself, a systemic difference of two units exists. A 2-unit systematic difference does not suggest perfect agreement, but would yield a perfect correlation of 1.0 (Pearson's *r*). Although comparing means using a *t*-test would provide indication that that the mother on average rated her son lower than he rated himself, this information is not given within the context of a statistic based on the "line of agreement" that can provide a wider perspective on overall agreement and type of linear relationship between the raters beyond the focal points of the means (Deyo et al., 1991; Lin, 1989). The line of agreement referred to is the 45 degree line that all points would fall along if perfect agreement was found between informants, given one informant's (or group of informants) ratings are plotted along the *y*-axis and the other informant's (or groups of informants) ratings are plotted along the *x*-axis. The product moment correlation also does not provide any information within the context of the line of agreement, only the strength of the relationship among ratings, which could follow along any linear trend located on any part of a graph (Martin & Altman, 1986). Overall, this first approach provides a basic view into differences in informant perspectives, with limitations that have lead researchers to use intraclass correlation.

The second approach to understanding informant variance utilizes the intraclass correlation and its statistic, the intraclass correlation coefficient (ICC). Eiser and Morse (2001a) explained the intraclass correlation to be "a measure of the proportion of overall variability accounted for by variability among individuals (individuals raters)" (p. 355-356) . This statistical measurement provides us with a more complete view (above and beyond product moment correlation) into the level of informant agreement as the "total variance" accounted for gives consideration to residual variance (i.e., variance due to error) and variance among raters (Kramer & Feinstein, 1981). Kramer and Feinstein (1981) explained the intraclass correlation to combine a measure of correlation with a test for comparison of means. This allows for the intraclass correlation to correct for systematic bias among ratings, which is reflected in the level of agreement indicated in the ICC (varying from -1 to 1). For example, a mother's ratings of a consistent two units lower than her son on every item would not yield a perfect correlation statistic of 1.0 as in a product moment correlation. Furthermore, the intraclass correlation is able to examine relation between informant ratings by not only comparing similarity in slopes, but similarity in intercepts as well, which analyzes

deviance from the line of agreement (see Kramer & Feinstein, 1981 for a review) . Ultimately, the intraclass correlation analysis provides investigators with a decent statistic of correlation for estimating the *agreement across informants*. The established guidelines for gauging level of agreement represented by the ICC is as follows: poor <0.30; moderate 0.30-0.50; and good >0.50 (see Upton et al., 2008 for review). As explained previously, in general, parent-child agreement in HRQOL is highest for physical domains and lower in social and emotional domains (see Eiser & Morse, 2001a and Upton et al., 2008 for reviews). Please note, these findings should be considered carefully, as they are expressed in reviews of parent child-agreement, including results from analyses utilizing both product moment and intraclass correlations weighted equally as measures of agreement.

Finally, a third approach to assessing variance among informants is by discrepancy analysis. Discrepancy analysis provides a contrasting perspective into disagreement among informants, as opposed to ICC analysis, which assesses for agreement. In other words, discrepancy analysis examines the degree to which *informant perspectives differ* and ICC analysis examines the degree to which they are *similar*. Although it may seem that that discrepancy analysis and ICC (agreement) analysis provides opposite and redundant informant, there has been no research to date specifically contrasting and comparing the utility of the two approaches to support this notion. One definitive difference, however, is that they vary by statistical approach.

There are three main differences in statistical approach when assessing discrepancy versus agreement. The first difference is that that discrepancy analysis does not include the use of a correlation statistic (i.e., Pearson's *r*, ICC; Truetler & Epkins, 2003). The second difference is that discrepancy analysis examines individual dyads among informant samples, rather than overall trends from one sample of informants to another (Sood et al., 2012). The third difference is that discrepancy analysis usually includes inputting difference scores from informant dyads into regressions and making predictions on a given criterion (see Holmbeck et al., 2002 for a review) .

Sood et al. (2012) described three most wildly used statistical procedures for discrepancy analysis. First, there is the practice of simply calculating difference scores, which entails taking the parent's (almost always mother) total score from a measure and subtracting the child's total score from a measure.

However, this method yields results that are confusing to analyze, as straightforward difference scores can lead to negative numbers. This creates curvilinear distributions that are difficult to interpret, especially when used in trying to predict a criterion (see Holmbeck et al. 2002 for a review). The next approach is similar, but it is the absolute values of the difference scores that are analyzed and used to make predictions. The advantage of this approach is that the absolute values remove the possibility and difficulty of using negative numbers for analysis. In addition, the absolute values of these differences can be easily entered as predictors for a particular criterion in a linear regression. However, as Sood et al. (2012) explained it, absolute values of difference scores can be difficult to interpret because they may reflect more than one type of dyad per individual difference score. For example, a mother who overrates her child by 20 units on any given measure may receive the same discrepancy score as a mother who underrates her child by 20 units due to the use of absolute values.

Sood et al. (2012) recommend an item-level analysis approach to analyzing discrepancies because this method provides the most detail regarding the nature of the discrepancy among informants and yields the absolute values of differences for each corresponding item for a measure that was completed by each informant. Sums of these values are calculated, which produces a discrepancy score for each dyad that suggests more discrepancy if higher and less discrepancy if lower on a given measure. Scores are then entered into a regression model as a predictor. Sood et al. (2012) described this item-level approach to better "accommodate differences on individual items" because using absolute value differences from total measure scores does not factor in notable variability that might come from greater or less disagreement on certain items. For example, a greater parent-child disagreement might be low for items 1 through 5 on a measure, but high for items 5 through 10. This would not be reflected by the results of analyzing informant differences of total scores from a measure, but will be reflected examining absolute differences at the item level. Although this method by Sood et al. (2012) may provide detail above and beyond that of the other two statistical procedures for assessing informant discrepancies, a limitation that these item-level absolute value difference scores may reflect more than one type of discrepant dyad at the item-level. This is similar to the problem with absolute value difference scores in the previously discussed statistical procedure, in

which absolute value difference scores reflected more than one type of discrepant dyad at the measure level.

Ultimately, research on informant discrepancies, in spite of differences in statistical procedures for analysis, can provide another piece of the puzzle to understanding the relation in perspectives between informants, and is increasingly becoming recognized and utilized (Achenbach, 2011; De Los Reyes et al., 2011). Traditionally, any differences in reporting across informants have been viewed as measurement error, but investigations into informant discrepancies have begun to consider varying informant ratings as not measurement error, but an opportunity for a deeper understanding. Recent perspectives into informant discrepancies are based on exploring differences in informant perspective for two purposes: (a) What does it mean when differing perspectives or discrepancies emerge across informants? (b) Can these discrepancies be used to better understand functioning in children, or various pediatric chronic health conditions? (De Los Reyes et al., 2011).

Scant literature exists that has taken the next step to investigate informant discrepancies for the purpose of observing what they may predict. For example, Beck, Hartos, and Simons-Morton (2006) showed that the level of disagreement (discrepancy) between teenagers and parents on appropriate driving conditions was positively associated with risky teen driving. In addition, Pelton and Forehand (2001) found that mother-teenager discrepancy in perceptions of mother-teenager relationship was associated with both teenager internalizing problems and externalizing problems as rated by mother. Also, Ferdinand, Van der Ende, and Verhulst (2006) found that parent-child discrepancies in symptoms reporting predicted poor treatment outcome 3.4 years after outpatient behavioral health treatment for children and adolescents 11 to18 years old. Moreover, Maurizi, Gershoff, and Aber (2012) found that discordance between adolescents and parents with regard to parental practices predicted adolescent self-report of anxiety, conduct disorder symptoms, and quality of parent-adolescent relationship.

Eiser and Varni (2013) recommended discrepancy analysis be applied to parent-child perspectives in HRQOL and disease-specific symptoms in children with chronic health conditions. This seems to be a logical progression because research into HRQOL has typically examined informant perspectives using means and standard deviations and intraclass correlations. Discrepancy analysis may

provide the next step toward a deeper understanding of HRQOL in pediatric chronic health conditions due to the possibility of making predictions using informant discrepancies. The ability to predict outcomes by examining the degree to which informants disagree might be a major asset to understanding how to cope with chronic health conditions and the ways in which it should be addressed. This work approach might be better able to help and encourage physicians, behavioral health professionals, and researchers to value differing perspectives on a given child's HRQOL for the unique contribution that each perspective might serve to helping understand the child's functioning. Furthermore, it seems logically inconsistent to develop HRQOL measures with multiple informant report forms and expect to obtain exact agreement, especially since they are given with the purpose of obtaining a varied perspective.

Researchers investigating chronic health conditions and HRQOL should work toward a better understanding of these informant discrepancies as an insightful piece of the larger picture, instead of completely viewing them merely as measure limitations or error in measurement. In addition to exploring statistical procedures for assessing agreement, the current study takes the next step forward toward discrepancy analysis of informant (parent-child) perspectives for ratings of HRQOL of children with GI disorders.

1.6 Summary

Given the literature reviewed here, it is evident pediatric chronic health conditions have a negative impact on HRQOL. Furthermore, the pervasiveness of GI disorders (Rentz et al., 2001), and the variety in which they manifest (Costa, Mumolo, Marchi, & Bellini, 2007), necessitate more investigation concerning HRQOL in pediatric GI dysfunction. It would be advantageous to start by considering the two broad categories in which GI disorders are grouped, specifically, FGIDs and OGIDs. To date, scant research exists regarding differences between FGIDs and OGIDs, and findings are mixed. A study by Warshburger et al. (2013) found no significant differences between FGID's and OGID's, in overall HRQOL and in functioning within the specific domains (physical, mental, self-esteem, family, and school) assessed. Furthermore, Youssef, Murphy, Langseder, and Rosh (2006) compared pediatric patients with functional abdominal pain and a group of OGIDs (Crohn's disease, Ulcerative Colitis, and gastroesophageal reflux disease), and found similar HRQOL between functional abdominal pain and the

OGIDs considered. Varni et al. 2006 compared HRQOL in pediatric patients with functional abdominal pain (a FGID), irritable bowel syndrome (a FGID), and various OGID's. HRQOL was found to be similar among all groups examined. Collectively, these findings above provide support to suggest comparable HRQOL between FGIDs and OGIDs.

Interestingly, in additional analyses, Varni et al. (2006) found children with functional abdominal pain (a FGID) or at least one OGID missed significantly more days of school, spent more days sick in bed or not healthy enough to play, and needed more days of sick care than children with irritable bowel syndrome (a FGID). Given that this comparison between FGIDs and OGIDs exemplified some differences between these two categories of GI disorders, differences may emerge between FGIDs and OGIDs with regard to HRQOL. A few reasons may be offered why research cited above did not find differences in HRQOL between FGIDs and OGIDs (Varni et al., 2006; Warschburger et al., 2013; Wolfe & Hanley, 2002; Youssef et al., 2006). First, functional abdominal pain was the primary FGID considered, and most frequent diagnosis within each sample of FGID groups studied. A greater diversity of FGID and OGID sample might highlight unique aspects of HRQOL and variance specific to each GI disorder type. In addition, a larger sample of FGIDs and OGIDs, in general, might further set the stage for enough heterogeneity between GI disorders types to further distinguish the two. A study addressing these weaknesses in research methodology might be able to better shed light on the differences between FGIDs and OGIDs, and further highlight differences between the two beyond variances in days missed from school, days sick in bed or not healthy enough to play, and more days sick care in need of care found in Varni et al. (2006).In addition, Varni et al. (2014) found that children with FGIDs showed more gastrointestinal symptoms and worry symptoms than children with OGIDs. These findings of greater impairment in children with FGIDs relative to children with OGIDs might be indicative of greater impairment in HRQOL specifically, as well

As stated previously, OGIDs can be traced to a specific medical etiology causing GI dysfunction and FGIDs have an unclear etiology. This difference in knowledge of etiology of illness may yield differences in HRQOL across groups. It is possible that knowledge or lack of knowledge of GI

dysfunction etiology may affect differences in quality and effectiveness of coping with that dysfunction to the extent that HRQOL is impaired differentially.

Research into possible differences in overall HRQOL and specific symptoms among FGIDs and OGIDs, might lead to indicators of a better approach in treatment and quality improvement for those coping with these disorders. Any identified differences between FGIDs and OGIDs will improve understanding of how to differentially treat GI disorders. Furthermore, FGIDs seem to be the most mysterious due to their lack of clear etiology, and, therefore, might be most in need of specific investigation. As etiology is unknown, research should emphasize the aspects of this disease group that are known and can be measured, and overall HRQOL and specific domains HRQOL can be where this begins. An examination of unique patterns of HRQOL for children with FGIDs, and children with OGIDs as a reference group, may lead to advances in knowledge of FGIDs, which may be helpful in the process of making them less mysterious, easier to cope with , and better treated.

In addition, variance in maturity and autonomy with age may lead to differences in child reported symptoms as related to parent proxy-report. In other words, as children grow, variance in perspectives from child to parent may differ and this is something worth investigating as well.

1.7 Hypotheses

The purpose of the current study was 2-fold. First, HRQOL and specific domains were compared across GI disorder types (FGID vs. OGID) and age. Second, informant variance in parent proxy-report versus child self-report on HRQOL were examined in terms of relatedness, agreement, and discrepancy. An emphasis was placed on the nature of the unique contribution for each type of analysis in explaining informant variance, and especially the predictive power of discrepancy analysis, because the extant literature has underscored this type of analysis to be in the forefront of understanding variance in informant perspectives. The following hypotheses were tested:

1. Across parent proxy-report and child self-report, children with FGIDs or OGIDs will differ in overall and specific domains (i.e., physical, emotional, social, and school functioning) of generic HRQOL, such that children with OGIDs will be rated higher in HRQOL in overall and specific domains relative to children with FGIDs.

a. Varni et al. (2014) found that children with FGIDs showed more gastrointestinal symptoms and worry symptoms than children with OGIDs. These findings of greater impairment in children with FGIDs relative to children with OGIDs might be indicative of greater impairment in HRQOL specifically, as well.

2. Across parent proxy-report and child-report, overall HRQOL and all specific domains will vary by age groups, such that adolescents (ages 13-18 years) and children (ages 8-12 years) will score higher in HRQOL relative to young children (5-7 years)
    a. This hypothesis is supported by Varni et al. (2003) who found young children ages 5-7 years self-reported significantly lower overall HRQOL than children ages 8-12 years and adolescents 13-16 years. In addition, similar, marginal differences in overall HRQOL were found according to parent-proxy report.
3. Parent proxy-report and child self-report ratings of overall and specific domains of HRQOL will differ, so as to suggest a direction for which informant ratings are higher or lower relative to the other. This direction will show parents proxy-reporting lower HRQOL than children in overall and in all specific domains of HRQOL.
    a. This hypothesis is supported by a review by Upton, Lawford, and Eiser (2008) pointed out that a recurring theme in the literature that parents of children with chronic health conditions tended to underestimate their children's HRQOL in proxy-reporting, relative to the children's self-report.
4. Parent-child agreement of HRQOL will vary between GI disorder types, such that children with OGIDs will have higher informant agreement than children with FGIDs.
    a. Previous literature supports little variance in parent-child agreement by child illness status, and some literature supports not difference at all (see Upton, Lawford, & Eiser, 2008 for review). However, it seems that the categorical distinguishing factor (knowledge of origin or lack of knowledge of origin) between these GI disorder types, might make for a unique comparison, which may exacerbate differences in agreement. Moreover, FGIDs have a unknown organic etiology, which may make it difficult for parents and children to anchor

their perspectives regarding the child's HRQOL and may be particularly influential to parent-child agreement, differentiating agreement between both GI disorder types.

5. Parent-child agreement will vary by age group, such that children(ages 8-12 years) will show highest agreement relative to young children (ages 5-7 years) and adolescents (13-18 years), which will have similar agreement.
    a. This hypothesis is supported by a review by Upton, Lawford, and Eiser (2008), which described that one study found young children to have lower parent-child agreement relative to other ages, and another study, which found adolescents to have lower parent-child agreement relative to other ages. Another study found adolescents to have highest parent-child agreement as measured by the Pearson product moment correlation (Varni, Burwinkle, Seid, & Skarr, 2003).
6. Parent-child discrepancies will significantly predict GI disorder type and specific GI disorders, such that greater discrepancies will be more predictive of FGIDs than OGID's. Specific GI disorders associated with the FGID category will show differences in individual comparisons GI disorders associated with the OGID category.
    a. Support for this hypothesis is based off of similar logic regarding agreement between GI disorder types as was described in hypothesis 4. Considering that FGIDs have an unknown organic etiology, which may make it difficult for parents and children to anchor their perspectives regarding the children's HRQOL,FGIDs should have particular influence on the degree of discrepancy between parents and children report of HRQOL for children with FGIDs, which should exacerbate parent-child discrepancies in reporting of HRQOL above and beyond that of parent-child HRQOL reporting for children with OGIDs.

2. METHOD

2.1 Participants

Participants included 548 children ranging from ages 5-18 years and their parents recruited from nine children's hospitals across the US including: Primary Children's Medical Center, Salt Lake City, UT, Cincinnati Children's Hospital Medical Center, Cincinnati, OH, Children's Memorial Hospital, Chicago, IL, Texas Children's Hospital, Houston, TX, Boston Children's Hospital, Boston, MA, Children's Hospital Colorado, Aurora, CO, Goryeb Children's Hospital/Morristown Memorial Hospital, Morristown, NJ, Nationwide Children's Hospital, Columbus, OH, and Children's Medical Center of Dallas, TX. At each location, patients with a GI disorder were asked to participate. Participants included in this study had a FGID (N = 264), or OGID (N = 284) type GI disorder and ages ranged from 5-18 years. Specific FGIDs included chronic constipation (N = 116), functional abdominal pain (N = 108), and irritable bowel syndrome (N = 40). Specific OGIDs included Crohn's disease (N = 184), ulcerative colitis (N = 60), and gastroesophageal reflux disease (N=40). Children were separated into three age groups, based on PedsQL™ 4.0 Generic Core Scales age groupings 5-7 years (N = 69), 8-12 years (N = 203), and 13-18 years (N = 276). . Race/ethnicity groups included were Black, Non-Hispanic (N = 51), Hispanic (N = 58), and White, Non-Hispanic (N = 439). Native American or Alaskan Native, Asian or Pacific Islander, and Other ethnic categories were excluded from analysis, because not enough participants were present in each category to allow for valid logistic regression models. James W. Varni, Ph.D. is the approved principal investigator of this study by the Texas A&M University Institutional Review Board (protocol number #IRB2011-0496), and I am the co-investigator.

2.2 Measures

Health-Related Quality of Life (HRQOL). The Pediatric Quality of Life Inventory™ (PedsQL™) 4.0 Generic Core Scales were used to measure generic HRQOL. The PedsQL™ Generic Core Scales is a generic measure of HRQOL assessing four domains of functioning (Varni, Seid, & Kurtin, 2001;Varni et al., 2003): physical, emotional, social, and school functioning (only considered in overall HRQOL for current study). Of the numerous PedsQL™ versions developed, this study included three PedsQL™ versions appropriate for ages 5-7 years (young child), 8-12 years (child), and 13-18 years (adolescent).

The age-appropriate PedsQL™ forms for children and adolescents s of the utilize a 5-point Likert scale ranging from 0 (never) to 4 (almost always) to signify nature of endorsement for each symptom described by each item. In addition, each parent proxy-report form utilized this same format for each age group. The PedsQL™ form designated for young children uses a simplified 3-point Likert scale, with scoring including 0 (not at all a problem), 2 (sometimes a problem), 4 (a lot of a problem). The PedsQL™ has been shown to have good reliability and validity with regard to psychometric performance (Varni et al., 2003; Varni, Seid, & Kurtin, 2001).

*Demographic Information***.** Parents completed the PedsQL™ Family Information Form, which provides a variety of demographic-type questions including race/ethnicity, age, date of birth, and gender. As shown in Table 3, descriptive statistics were used to calculate frequencies for each specific GI disorder primary diagnoses and all relevant demographic information including age, gender, and race/ethnicity.

2.3 Procedure

After providing informed consent and assent, participants (children and parents) were individually administered a paper form of the PedsQL™ 4.0 Generic Core Scales and asked to mark their answers for each item with regard to patient (the child's) functioning. Parents were also asked to complete the PedsQL™ Family Information Form. Participants were encouraged to answer all items but allowed to refrain from answering any particular item they felt uncomfortable answering. They were also given the option to stop their participation at any time.

2.4 Statistical Analyses

All items were reverse scored and linearly transformed to provide scores from 0-100 with higher scores denoting better overall HRQOL or functioning in specific domains. Ten 2-way ANOVAs tested for the effects of GI disorder type (FGID vs. OGID), age groups (young child = 5-7 years old, child = 8-12 years old, adolescents = 13-18 years old) and their interactions on overall HRQOL, and the specific domains of physical, emotional, social, and school functioning, according to scores on PedsQL™ 4.0 Generic Core Scales for child self-report and parent proxy-report. Five *t*-tests tested for significant differences between average ratings of child self-report and parent proxy-report for overall HRQOL and specific domains. Agreement was measured separately among GI disorder types and age groups using two

separate intraclass correlations. Assessment of overlapping confidence intervals was used to determine significant differences between GI disorders and age groups. A single binary logistic regression was utilized to predict GI disorder type from child self-report and parent proxy-report discrepancy scores. Five multinomial logistic regressions (each with a different GI disorder used as a reference category) were utilized to predict GI disorder from child self-report and parent proxy-report discrepancy scores. Although the omnibus test revealed the same results across each multinomial logistic regression, change in reference category for each regression revealed all possible pairwise comparisons between GI disorders. Item level discrepancy scores were calculated based on the procedure for calculating item level discrepancies described in Sood et al. (2012). This procedure consists of first subtracting all items from the child-self report from each corresponding item of the parent-proxy report of the PedsQL^{TM} 4.0 Generic Core Scales. Next, the absolute value of each item difference was generated and each item-level absolute value difference for each dyad was collectively summed to calculate an overall discrepancy score for each dyad. Greater discrepancy scores indicate greater degree of discrepancy/discordance. Discrepancy scores were entered as predictors in logistic regressions.

3. RESULTS

3.1 Overall HRQL-Child Self-Report

No main effect of age group was found, F (2, 524) = 2.56, p =.078, η^2 =.01. A main effect of GI disorder type was found, F (1, 524) = 18.14, p < .001, η^2 = .033 such that the average HRQOL score was higher for children with OGIDs (M = 77.96, SD = 14.70) than for children with FGIDs (M = 69.73, SD = 16.97; See Figure 1). No significant interaction of age group and GI disorder type was found, F (2, 524) = .651, p = .511, η^2 = .002.

3.2 Overall HRQL-Parent Proxy-Report

No main effect of age group was found, F (2, 521) = 1.80, p =.166, η^2 =.007. A main effect of GI disorder type was found, F (1, 521) = 14.99, p < .001, η^2 = .028 such that the average HRQOL score was higher for children with OGIDs (M = 75.95, SD = 16.89) than for children with FGIDs (M= 67.09, SD=19.08; See Figure 2). No significant interaction of age group and GI disorder type was found, F (2, 524) = .761, p = .468, η^2 = .003.

3.3 Physical Functioning – Child Self-report

No main effect of age group was found, F (2, 524) = 2.98, p = .052, η^2 =.011. A main effect of GI disorder type was found, F (1, 524) < 13.51, p < .001, η^2 = .025, such that average physical functioning score was higher for children with OGIDs (M = 80.25, SD = 16.71) than for children with FGIDs (M = 72.59, SD = 20.33). No significant interaction of age group and GI disorder type was found, F (2, 524) = .954, p = .386, η^2 = .004.

3.4 Physical Functioning – Parent Proxy-report

No main effect of age group was found, F (2, 521) = 2.04, p = .13, η^2 =.008. A main effect of GI disorder type was found, F (1, 521) = 11.63, p = .001, η^2 = .022. such that average physical functioning score was higher for children with OGIDs (M = 78.63, SD = 19.77) than for children with FGIDs (M = 68.86, SD = 23.22). No significant interaction of age group and GI disorder type was found, F (2, 521) = 1.96, p = .14, η^2 = .007.

3.5 Emotional Functioning-Child Self-Report

A main effect of age group, F (2, 523) = 3.205, p = .04, η^2 =.012. However, post hoc pairwise comparisons revealed no significant differences among age groups, without consideration to GI disorder type. A main effect of GI disorder type, F (1, 523) = 7.89, p = .005, η^2 = .015, such that average emotional functioning score was higher for children with OGIDs (M = 74.92, SD = 21.10) than for children with FGIDs (M= 65.91, SD= 23.67). A significant interaction of age group and GI disorder type was found, F (2, 523) = 3.22, p = .041, η^2 = .012. Post hoc simple effects test revealed significant differences among age groups for children with OGIDs, such that young children ages 5-7 years (M = 75, SD = 22.12) and children ages 8-12 years (M = 67.43, SD = 23.13) rated themselves higher in emotional functioning than adolescents ages 13-18 years (M = 59.33, SD = 23.43).

3.6 Emotional Functioning – Parent Proxy-report

No main effect of age group was found, F (2, 521) = .485, p = .62, η^2 =.002. A main effect of GI disorder type was found, F (1, 521) = 8.40, p = .004, η^2 = .016 such that average emotional functioning score was higher for children with OGIDs (M = 70.93, SD = 21.61) than for children with FGIDs (M = 61.79, SD = 24.60). No significant interaction of age group and GI disorder type was found F (2, 521) = 1.19, p = .30, η^2 = .005.

3.7 Social Functioning-Child Self-Report

A main effect of age group, F (2, 524) = 3.35, p=.036, η^2 =.013, such that average social functioning was higher for the adolescents ages 13-18 years (M = 86.31, SD = 15.93), than children ages 8-12 years (M = 80.69, SD = 20.23) and young children ages 5-7 years (M = 78.40, SD = 19.13), who scored similarly. A main effect of GI disorder type was found, F (1, 524) = 14.20, p = .001, η^2 = .026 such that average social functioning score was higher for OGIDs (M = 87.43, SD = 19.56) than for FGIDs (M = 78.80, SD = 19.38). No significant interaction of age group and GI disorder type was found, F (2, 524) = .68, p = .507, η^2 = .003.

3.8 Social Functioning-Parent Self-Report

No main effect of age group, F (2, 521) = 1.01, p=.364, η^2 =.004. A main effect of GI disorder type was found, F (1, 521) = 8.77, p = .003, η^2 = .017 such that average social functioning score was

higher for OGIDs (M = 83.21, SD = 18.99) than for FGIDs (M = 76.77, SD= 21.76). No significant interaction of age group and GI disorder type was found F (2, 521) = .961, p = .383, η^2 = .004.

3.9 School Functioning-Child Self-Report

A main effect of age group was found, F (2, 523) = 7.52, p=.001, η^2 =.021, such that young children ages 5-7 years (M = 69.33, SD = 20.50) and children ages 8-12 years (M = 65.96, SD = 22.26) rated themselves higher in school functioning than adolescents ages 13-18 years (M = 61.73, SD = 21.77). A main effect of GI disorder type was found, F (2, 523) = 11, p = .001, η^2 = .021 such that average school functioning score was higher for children with OGIDs (M = 67.93, SD = 20.60) than for children with FGIDs (M = 60.02, SD = 22.67). No significant interaction of age group and GI disorder type was found, F (2, 524) = .558, p = .573, η^2 = .002.

3.10 School Functioning-Parent Proxy-Report

No main effect of age group, F (2, 515) = 2.303, p=.101, η^2 =.009. A main effect of GI disorder type, F (1, 515) = 9.85, p = .002, η^2 = .019 such that average school functioning score was higher for children with OGIDs (M = 69.45, SD = 22.19) than for children with FGIDs (M = 59.84, SD = 24.76). No significant interaction of age group and GI disorder type was found, F (2, 515) = 1.28, p = .278, η^2 = .005.

3.11 Comparison of HRQOL between Child Self-Report and Parent Proxy-Report

A significant difference between child self-report and parent proxy-report with regard to overall HRQOL was found, t (1037.37) = 2.26, p = .024; d = .14 such that child self-report (M = 74.06, SD = 16.32) was higher than parent proxy-report (M = 71.64, SD =18.51). A significant difference between child self-report and parent proxy-report with regard to physical functioning was found, t (1028.91) = 2.17, p = .03; d = .13, such that child self-report (M = 76.62, SD = 18.88) was higher than parent proxy-report (M = 73.89, SD = 22.04). A significant difference between child self-report and parent proxy-report with regard to emotional functioning was found, t (1055) = 2.93, p = .004; d = .18, such that child self-report (M = 70.66, SD = 22.78) was higher than parent proxy-report (M = 66.49, SD = 23.53). A significant difference between child self-report and parent proxy-report with regard to social functioning was found, t (1038.341) = 2.69, p = .007; d = .17 such that child self-report (M = 83.30, SD = 18.26) was higher than

parent proxy-report (M = 80.08, SD = 20.62). No significant difference between child self-report and parent proxy-report with regard to school functioning, t (1037.37) = 2.26, p = .68.

3.12 Agreement among GI disorder types and Age groups

A significant intraclass correlation was found between child self-report and parent proxy report for children with OGID's ICC (266) = .64, p < .001, 95% CI for ICC (.56 - .71), and FGIDs, ICC (245) = .64, p < .001, 95% CI for ICC (.57 - .71). These ICCs indicate good agreement among raters for across GI disorder types (Varni, Limbers, & Burwinkle, 2007). In addition, comparison of GI disorder types using 95% confidence intervals revealed no significant difference of intraclass correlation between GI disorder types. Furthermore, a significant intraclass correlation was found between child self-report and parent proxy report for young children (5-7 years), ICC (58) = .54, p < .001, 95% CI for ICC (.33 - .70), children (8-12 years), ICC (192) = .727, p < .001, 95% CI for ICC (.63 - .78), and adolescents (13-18 years), ICC (260) = .63, p < .001, 95% CI for ICC (.63 - .71). These ICCs indicate fair (5-7 years) to good (8-12 and 13-18 years) agreement among raters across age groups (see Upton et al. 2008 for review). In addition, comparison of age groups using 95% confidence intervals revealed no significant difference of intraclass correlation between age groups.

3.13 Discrepancy Analysis Predicting GI Disorder Type

To find the unique variance predicted by discrepancy scores (between child self-report and parent proxy-report), discrepancy scores, age, race, and gender were entered into a binary logistic regression model for predicting GI disorder type, $\chi^2(4) = 88.42$, $p < .001$. This suggests that these set of predictors account for a significant amount of variance distinguishing between GI disorder types. More specifically, holding age, race, and gender constant, discrepancy scores individually predicated GI disorder type $\chi^2(1) = 14.787$, $p < .001$, Exp (B) = 1.002. The corresponding odds ratio [Exp (B)] indicates that every unit increase in discrepancy score is associated with a 1.002 change in likelihood that a child with a GI disorder will be classified with a FGID (M = 477.92, SD = 242.75), rather than an OGID (M = 393.96, SD = 218.03).

3.14 Discrepancy Analysis Predicting Specific GI Disorder

To find the unique variance predicted by discrepancy scores (between child self-report and parent proxy-report), discrepancy scores, age, race, and gender were entered into a multinomial logistic regression model for predicting GI disorder type, $\chi^2(25) = 225.131$, $p < .001$. This suggests that these set of predictors account for a significant amount of variance distinguishing between specific GI disorders. Table 3 shows a summary of results for all pairwise comparisons between GI disorder types as predicted by child self-report and parent proxy-report discrepancy scores, holding constant age, gender, and ethnicity. Significant comparisons are between Crohn's Disease ($M = 395.89$, $SD = 211.61$) and Chronic Constipation ($M = 511.15$, $SD = 265.38$), $\chi^2(1) = 12.25$, $p < .001$, Exp (B) = 1.002, Ulcerative Colitis ($M = 367.95$, $SD = 180.54$) and Chronic Constipation (M = 511.15, SD = 265.38) $\chi^2(1) = 12.322$, $p < .001$, Exp (B) = 1.003, Crohn's Disease (M = 395.89, SD = 211.61) and Functional Abdominal Pain ($M = 464.76.92$, $SD = 224.07$), $\chi^2(1) = 6.71$, $p = .010$, Exp (B) = 1.002, and Ulcerative Colitis ($M = 367.95$, $SD = 180.54$) and Functional Abdominal Pain ($M = 464.76.92$, $SD = 224.07$), $\chi^2(1) = 8.19$, $p = .004$, Exp (B) = 1.002. Each corresponding odds ratio [Exp (B)] indicates that every one unit increase in discrepancy score is associated with that odds ratio's [Exp (B)] change in likelihood that a child will be classified with the latter mentioned GI disorder, rather than the former mentioned GI disorder.

4. SUMMARY AND CONCLUSIONS

4.1 Summary

One of the main purposes of the current study was to investigate possible differences in HRQOL among GI disorder type (FGID's vs. OGIDs), and it was proposed that children with FGIDs would be rated worse in HRQOL than children with OGIDs. Research findings by Warshburger et al. (2013) and Youssef, Murphy, Langseder, and Rosh (2006) support similar HRQOL between these two GI disorder types, but findings by Varni et al., (2014) reported some differences based on other indices. Findings by the current study consistently support differences in HRQOL between GI disorder types, for overall HRQOL, across specific domains of HRQOL, and across informant reports. In addition, medium to large effect sizes were found for these differences in HRQOL between GI disorder types across all analyses. These data are consistent with findings by Varni et al. (2006), which found that children with functional abdominal pain, a FGID, or at least one OGID missed significantly more days of school, spent more days sick in bed or not healthy enough to play, and needed more days of sick care than children with irritable bowel syndrome, also a FGID. Although these differences are not direct measures of HRQOL, these practical indices suggest that some difference exist between FGIDs and OGIDs, and this is consistent with our findings. More specifically, children with an FGID were rated worse in HRQOL than children with OGIDs consistently across informants and with regard to overall HRQOL and each dimension. These findings are also supported by Varni et al. (2014), which found that children with FGIDs show more symptoms of GI disorder and worry than children with OGIDs. Ultimately, findings of the current study support our first hypothesis and the speculation that knowledge or lack of knowledge of GI dysfunction etiology may affect differences in quality and effectiveness of coping with that dysfunction to the extent that HRQOL is impaired differentially.

In addition, it was proposed that HRQOL would vary by age group in children with GI disorders. A difference was found in the area of social functioning, such that adolescents self-reported higher social functioning than children, and young children, which may suggest better coping strategies in the area of social functioning for children with GI dysfunction in later years. However, the reverse effect was found for school functioning. Adolescents self-reported worse school functioning than children, and young

children. Collectively, these findings suggest that children with GI disorders cope with their GI dysfunction in ways that help them get along better and keep up with their peers as they get older, but are more impaired in their school functioning as they grow into their adolescent years. This may be because as school becomes more challenging into adolescent years, GI problems have a greater opportunity to disturb their schoolwork, and their ability to attend and stay organized in school. Furthermore, a significant interaction of age and gender reveals that children with OGIDs vary in emotional functioning by age group. Adolescents with OGIDs rated themselves worse in emotional functioning than children, and young children. Although children with OGIDs generally report better emotional functioning than children with FGIDs, they are differentiated by age group, which may further shed light on the idea that GI dysfunction is associated with greater impaired relative functioning for adolescents, than younger age groups, as was found with school functioning. These findings partially support our second hypothesis, which predicted young children would be more impaired in HRQOL relative to the older age groups, as this was found for social functioning specifically. Besides this finding, hypothesis 2 was not supported.

Furthermore, the current study investigated possible differences and the directionality of those differences in reported HRQOL among informants. In other words, the current study evaluated as to whether children or parents rated their children higher or lower in HRQOL relative to each other. Findings revealed that children and parents reported significantly different scores for overall HRQOL and the domains of physical, emotional, and social functioning. However, Cohen's *d* suggested only small effect sizes for these differences. Children and parents reported similar average scores in school functioning. Overall, these findings are consistent with previous findings that parents of children with chronic health conditions generally underestimate their child's HRQOL, relative to the children themselves (See Upton, Lawford, & Eiser, 2008 for review), and support our third hypothesis. Children and parents might report similarly regarding to school functioning due to obvious indicators such as grades and teacher feedback, which might provide a better anchor for allowing parents and children to understand children's' school functioning in the same way.

Hypotheses four and five predicted parent-child agreement of HRQOL would vary by GI disorder type and age group. These hypotheses were not supported. Direct comparison of confidence intervals (i.e.,

assessing of non-overlapping confidence intervals for significant difference between correlations) was used to assess differences between groups, and this is considered to be a very conservative significance test between correlations (Wolfe & Hanley, 2002). Good agreement was found among all groups considered; however, some variation emerged, albeit non-significant, between age groups for children with GI disorders. Children with GI disorders showed the best parent-child agreement (ICC=.726) for children, relative to young children (ICC=.54), and adolescents (ICC=.63). This might be a trend providing support that the age period of 8-12 years is the point at which agreement is the best for children with GI disorders, because their communication skills are more developed than young children, allowing for better agreement. Furthermore, they may still be at a developmental point where they have not individuated as much from their parents as adolescents, which also allows for better agreement for children in this comparison. Further analysis using a test with greater sensitivity for differences between ICCs, such as that developed by Ramasundaraghettige, Donnder, and Zou, (2009), might be used to yield significant differences in ICCs between child age groups.

The final hypothesis was regarding discrepancy scores, and the use of discrepancy scores to predict GI disorder type, and specific GI disorder. It was found that FGIDs were at a greater likelihood to be associated with increased discrepancy scores than OGIDs. This association with greater discrepancy scores for FGIDs was further emphasized in comparisons of specific GI disorders, as each significant comparison involved a specific FGID to be associated with greater likelihood of increased discrepancy scores than a specific OGID. These findings support our sixth and final hypothesis.

4.2 Conclusions

The overall findings of the current study reveal notable differences between FGIDs and OGIDs regarding level of HRQOL and variance in perspective between informant perspectives. Children with FGIDs were significantly more impaired in overall HRQOL, and in all specific domains of HRQOL (i.e., physical, emotional, social, and school functioning). In addition, children with FGIDs were at a greater likelihood of higher discrepancies between child self-report and parent proxy-report than children with OGIDs. Given these data, the lack of knowledge of the etiology of a pediatric GI disorder is more associated with impaired HRQOL and variance in perception between child and parents of the child's

HRQOL than pediatric GI disorders of known etiology. These findings provide great insight into the severity of FGIDs over OGIDs. Furthermore, insight into the variation between parent and child perspective provides unique and helpful guidance into describing a fuller picture as to how experience with a FGID might be different than an experience with an OGID. In addition to considering that children with FGIDs are more impaired in HRQOL than OGIDs in overall HRQOL and all specific domains, quality improvement can be further understood by helping to close the gap between child perspective and parent perspective of the child's experience.

Furthermore, informant perspectives of child self-report and parent proxy-report were examined in terms of relatedness, agreement, and discrepancy. The relatedness analysis provided insight into directional differences in reporting among informants and the fact that parents reported worse HRQOL for the children, than the children themselves report. Agreement analysis provided insight onto the overall strength of agreement, which was maintained across GI disorder and ages, although comparisons among age groups revealed as a non-significant trend. Lastly, discrepancy scores revealed differences in likelihood of increased informant discrepancies between GI disorder types.

Regarding variance in informant perspective between GI disorder types, the relatedness analysis and discrepancy analysis described more the differences in perspective, while the agreement analysis revealed how much these informant perspectives were the same. Discrepancy and relatedness analysis provided one side of the perspective to understanding informant variance, and agreement analysis seemed to provide the other. In other words, although ICCs may reveal good agreement, they do not necessarily provide complete insight as to the degree to which informant perspectives disagree. However, as found in this study, the relatedness analysis only revealed small effects sizes regarding straight differences in informant perspectives, and discrepancy analysis revealed only small likelihoods (albeit significant) that FGIDs were likely to be higher in discrepancy scores. Therefore, good agreement apparently can be consistent with modest, yet noticeable, differences in informant perspectives.

Findings from the current study suggest that children with FGIDs, are more impaired in quality of life relative to children with OGIDs and are more discrepant among informants in reporting of HRQOL. This evidence is sufficient to re-think and modify the type of evidence-based practices used to treat these

pediatric chronic health conditions. Such modifications should commence with efforts to reduce the level of discrepancy among informants and provide a better understanding among informants about a child's health condition and functioning as it relates to generic HRQOL. Generic HRQOL concerns developmentally critical areas of functioning for every child, and it is seems logical to believe that improving parent's and child's understanding of each other's perspective should cultivate a situation in which is it easier to improve a child's physical, social, emotional, and school functioning.. Less disagreement between parents and children should reduce the "mysteriousness" of FGIDs, and help the parent and child better express to health service providers the intensity, frequency, and quality of target issues globally affecting the child's functioning. This should create better odds in being able to effectively address quality improvement for health services and maintenance of chronic health condition in everyday life.

Furthermore, these findings point toward more research into HRQOL for children with GI disorders. Better understanding which dimensions of HRQOL gives more weight to overall quality life would provide insight into to which dimensions are more critical than others to a child's overall functioning, and better signal how to address HRQOL issues in children with GI disorders. This can be done through the use of a regression model with each average score of each dimension individually entered as predictors for overall HRQOL. Then, effect size coefficients can be used to understand which significant predictions have the biggest impact on overall HRQOL.

In addition, more research must occur regarding agreement and item-level discrepancy research. The use of a recent innovative significance test by Ramasundaraghettige, Donnder, and Zou (2009) for differences between ICCs would provide a statistical test more tailored for and sensitive to differences between ICCs, yeild a more accurate understanding of variance among ICCs, and shed light better on noteworthy differences between ICCs for measuring agreement between age groups and GI disorders.

In addition, a better developmental picture can be provided through the use of item-level informant discrepancies for predicting differences in association of discrepancies between age groups and genders among children with GI disorders. This would allow for a better understanding of the quality of informant variance that may exist between genders and age groups, with implications for healthy children

and children with other chronic pediatric health conditions. Furthermore, similar implications can be made when comparing average scores of HRQOL by gender, for a better developmental understanding of the difference of impairment of HRQOL between genders for children with GI disorders

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APPENDIX A

FIGURES

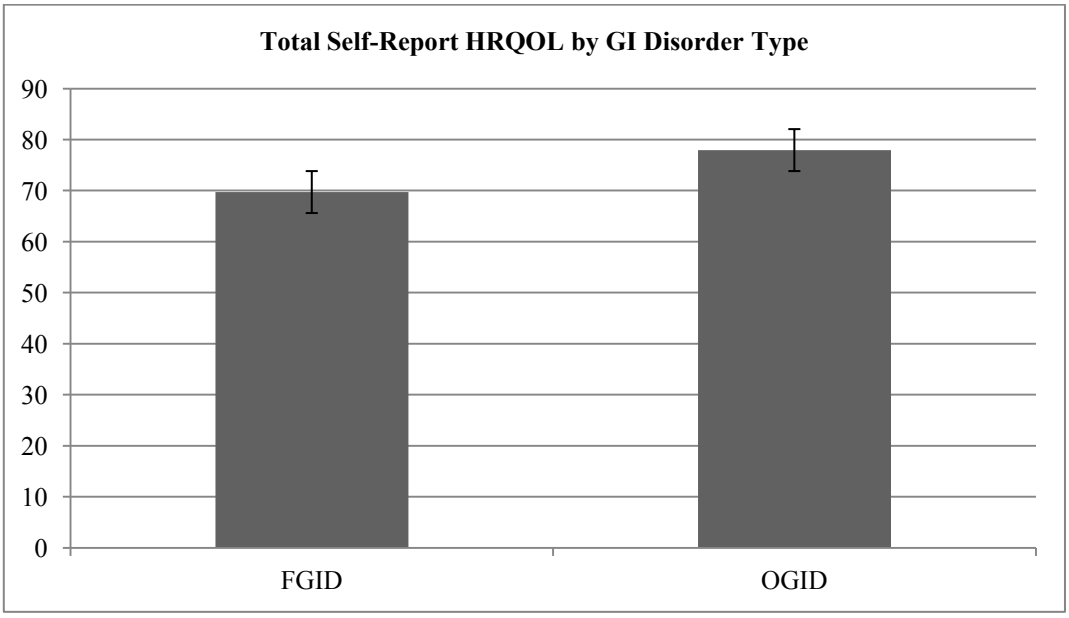

Figure 1 Total Self-Report HRQOL by GI Disorder Type

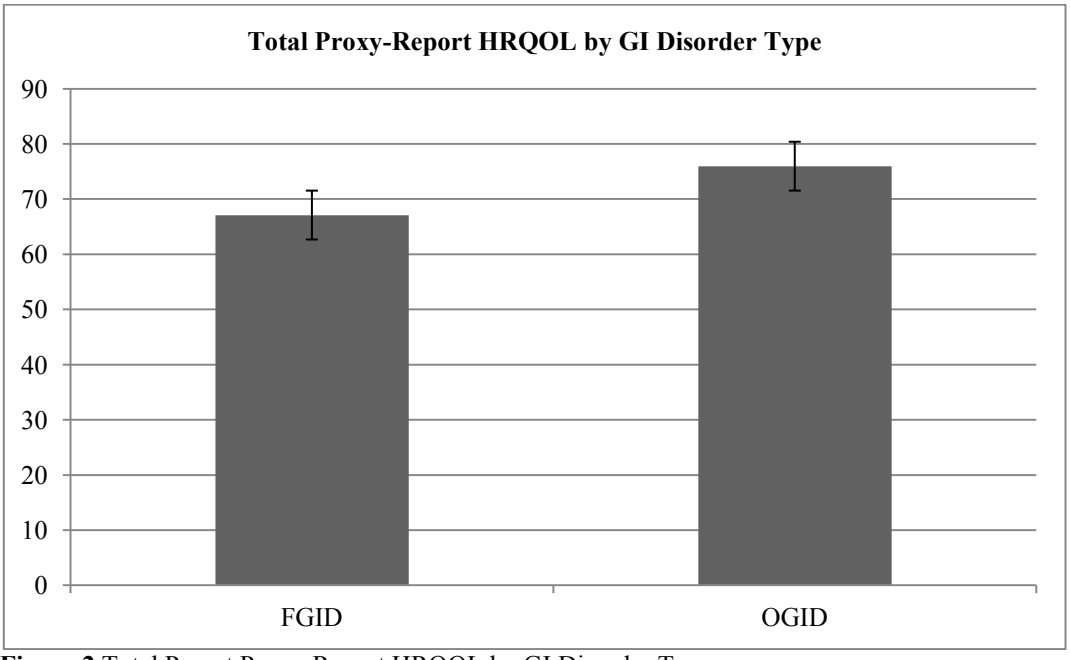

Figure 2 Total Parent Proxy-Report HRQOL by GI Disorder Type

APPENDIX B

TABLES

Table 1 Descriptive Statistics of Sample

N = 548

	Mean	**Standard Deviation**	**Range**
Age *(in years)*	12.66	3.66	5.00 - 18.92
Gender		**Frequency**	**Percent Total**
Female		257	46.9
Male		291	53.1
Age Group		**Frequency**	**Percent Total**
5-7 Years		69	12.6
8-12 Years		203	37
13-18 Years		276	50.4
Ethnicity		**Frequency**	**Percent Total**
Black (Non-Hispanic)		51	9.3
Hispanic		58	10.6
White (Non-Hispanic)		439	80.1
GI Disorder Type		**Frequency**	**Percent Total**
FGID		264	48.2
Chronic Constipation		116	21.2
Functional Abdominal Pain		108	19.7
Irritable Bowel Syndrome		40	7.3
OGID		284	51.8
Crohn's Disease		184	33.6
Ulcerative Colitis		60	10.9
Gastroesophageal Reflux Disease		40	7.3

Table 2 Advantages and Disadvantages of Various Statistical Approaches used for Assessing Informant Variance

Type of Analysis	**Statistical Approach**	**Advantages**	**Disadvantages**
1. **Relatedness**	Comparison of Means, Standard Deviations, and effect sizes,	-Can assess for significant or non-significant differences in average ratings across informants -Can assess direction of differences in average informant ratings and magnitude of difference	-Not sensitive to variance between informants -Not sensitive to deviance from 45 degree line of agreement
	Product Moment Correlation (Correlation using Pearson's *r*)	-Can measures linear relationship between informant ratings -Can provide some, albeit, not exhaustive support for agreement between informants, -Can compare variables of different metrics and variance -Can offer some support to measure's reliability	Not sensitive to systematic differences in informant ratings -Not sensitive to variance between informants -A significant correlation does not, in and of itself, allow exhaustive support for agreement -Is not sensitive to deviance from 45 degree line of agreement
2. **Agreement**	ICC	-Can measures agreement between informants, -Is sensitive to systematic difference in informant ratings -Is sensitive to variance between informants, -Can assess differences in agreement using confidence intervals -Is sensitive to magnitude of difference between informants -Is Sensitive to deviance from 45 degree line of agreement	-Measures only degree to which informants agree (not the degree to which they disagree or are discrepant)
3. **Discrepancy**	Difference Scores	-Provides difference scores that can be used as a predictor in regression	-Allows for negative difference scores, yielding curvilinear distributions difficult to interpret
	Absolute Value of Difference Scores	-Provides absolute value difference scores that can be used as a predictor in regression	-Allows for ambiguous informant dyads -Is only sensitive to differences in overall discrepancy scores
	Item-Level (absolute value) Discrepancy	-Provides item-level absolute value difference scores that can be used as a predictor in regression -Provides a statistic for assess level of discrepancy among informants	-Allows for ambiguous item-level informant dyads

Table 3 Pairwise Comparisons among Gastrointestinal Disorders

	Chronic Constipation	**Functional Abdominal Pain**	**Irritable Bowel Syndrome**	**Chrohn's Disease**	**Chrohn's Disease**
Chronic Constipation (*M* = 511.15, *SD* = 265.38)					
Functional Abdominal Pain (*M* = 464.76, *SD* = 224.07)	$\chi^2(1) = .98$, $p = .322$, Exp (B) = .1.001				
Irritable Bowel Syndrome (*M* = 421.76, *SD* = 216.74)	$\chi^2(1) = 2.90$, $p = .089$, Exp (B) = .1.002	$\chi^2(1) = 1.173$, $p = .279$, Exp (B) = 1.001			
Crohn's Disease (*M* = 395.89, *SD* = 211.61)	$\chi^2(1) = 12.25$, $p < .001$, Exp (B) = 1.002*	$\chi^2(1) = 6.71$, $p = .010$, Exp (B) = 1.002*	$\chi^2(1) = .417$, $p = .519$, Exp (B) = 1.001		
Ulcerative Colitis (*M* = 367.95, *SD* = 180.54)	$\chi^2(1) = 12.322$, $p < .001$, Exp (B) = 1.003*	$\chi^2(1) = 8.19$, $p = .004$, Exp (B) = 1.002*	$\chi^2(1) = 1.75$, $p = .187$, Exp (B) = 1.001	$\chi^2(1) = 1.10$, $p = .294$, Exp (B) = 1.001	
Gastroesophageal Reflux Disease (*M* = 423.63, *SD* = 287.15)	$\chi^2(1) = 2.893$, $p = .089$, Exp (B) =1.001	$\chi^2(1) = .89$, $p = .344$, Exp (B) = 1.001	$\chi^2(1) = .03$, $p = .858$, Exp (B) = 1.00	$\chi^2(1) = .904$, $p = .342$, Exp (B) = .998	$\chi^2(1) = 2.53$, $p = .112$, Exp (B) = .998

*Denotes significant difference in likelihood of higher discrepancy scores between GI Disorders.
Means and Standard Deviations of total discrepancies scores are within parenthesis adjacent to titles of GI Disorders.

Table 4 Discrepancies Mean (SD) and Percentage of Discrepancies for the PedsQL™ 4.0 Generic Core Scales

Generic Core Scales	Functional Gastrointestinal Disorders				Organic Gastrointestinal Disorders				Differences Means	Differences Percentages
	N	*M*	*SD*	*Percent*	*N*	*M*	*SD*	*Percent*		
Total Scale Score	246	12.42	4.82	54.15	267	11.03	4.81	48.16	1.39*	6.00*
Physical Health	246	3.90	2.17	48.86	267	3.51	2.10	43.82	.40*	5.04*
Psychosocial Health	246	8.52	3.45	56.97	267	7.52	3.54	50.46	1.00*	6.52*
Emotional Functioning	246	3.00	1.51	60.24	267	2.80	1.56	55.96	.20	4.29
Social Functioning	246	2.59	1.57	51.71	267	2.15	1.67	42.92	.44*	8.79*
School Functioning	244	2.96	2.61	59.26	264	2.61	1.49	52.20	.35*	7.07*

Note: *N* = number; *M* = mean; *SD* = standard deviation.
*$p<.05$ based on independent samples *t*-tests. Effect sizes are designated as small (.20), medium (.50), and large (.80)